

'Living with Metastatic Breast Cancer'

Better policy for metastatic cancer patients

First Policy Breakfast

6 April 2016



On 6 April 2016, Pfizer hosted a policy breakfast meeting on 'Living with metastatic breast cancer', the first in the series of 'Better Policy breakfasts' focusing on patients with metastatic cancer. The meeting gathered a variety of participants including patient and health advocates, healthcare professionals, Members of the European Parliament, industry representatives and public affairs consultants (see participant list in Annex 1). The breakfast conversation was moderated by Tamsin Rose and held between two guest speakers who made a significant effort to come to Brussels and share their experience: **Adrienne Veraart** from Borstkankervereniging Nederland (BVN), a Dutch breast cancer patient organisation, and **Gabriele Herzog** from Europa Donna Austria – both being metastatic breast cancer (mBC) patients.

The meeting was opened with a supportive message from Europa Donna's regional organisation, in which they re-affirmed their long-term commitment to improving the quality of life of metastatic breast cancer patients. Gabrielle and Adrienne then gave an honest account of living with metastatic breast cancer, including the impact on their personal and professional lives and the ups and downs of treatment. Adrienne, a local politician, was working 60 hour weeks; by changing the way she worked with her civil servants, she was able to see out her mandate but not seek re-election. She then worked part time, but finally had to stop that too. Gabrielle, an accountant, initially continued to work and had supportive colleagues, but left when it was felt that no suitable arrangement could be found for her to continue her regular work.

→ **Both speakers raised the issue of stigma around being a metastatic cancer patient.** They noted that a decreasing role in society was perhaps an inevitable aspect of a terminal condition. As

Adrienne put it, “I have to accept that my world has become smaller, and I can’t do all the things I like to do.” But there is misunderstanding: people either assume that after treatment they “can do everything again”, or assume they would die soon. But “because of better treatments, the time between diagnosis and death gets longer and longer” (Adrienne). Therefore, they highlighted the importance of being treated as more than ‘a disease’. In order to address this, Adrienne and BVN have produced a film giving insights into the different lives of three mBC patients. Meanwhile, Gabriele noted that having started as a student after her diagnosis, some people know she has mBC but “most just know me as a person”.

- **Regarding employment, Adrienne and Gabriele shared the challenges they experience in trying to adjust to the new routine and limitations to their daily work schedule whilst being metastatic cancer patients.** Flexibility of working schedules was indicated by both speakers as one of the areas where substantial improvements could be made and which, in the end, could contribute to maintaining the overall quality of life of metastatic cancer patients.
- **Relationships with family can be challenging to deal with, and benefit from support.** Families of metastatic cancer patients often have to deal with the practicalities of caring for a patient as well as dealing with the diagnosis. This requires support at a practical level (as discussed by Stecy Yghemenos below), but also a psychological one. Gabriele referred to the ‘Lifestyle Ambulance centre’ where she and her family receive support. This is a free service offered to metastatic cancer patients and their families at the Salzburg university hospital that combines an information centre, psychological support, and leisure activities for patients and families affected. Gabriele talked about this centre as crucial in helping her maintain her quality of life after the diagnosis, but noted that she knows such support is unusual across the EU. Adrienne noted that in the Netherlands, family support depends on terms of insurance policies and is not free of charge, representing a burden for those patients with fewer resources.
- **Maintaining a good quality of life is crucial to mBC patients.** Both speakers noted the dominant role of hospital visits in their lives (Gabriele: “the hospital sets the rhythm of my life ... I have to live on the days in between chemo”). However, different factors impact their overall quality of life (treatment effects, their mental status, activities in which they are engaged, family wellbeing, etc.).
- **Well-coordinated care makes a big difference.** Psycho-social support integrated into treatment programmes was beneficial to both speakers.
- **Communicating about the disease remains a challenge.** It can be difficult to talk about these things with the family (Gabriele writes letters to her son, while Adrienne makes recordings of fairytales that can be kept for her future grand-children, after agreement from her children). Better information is also needed to complement that provided within doctors’ offices.
- **Physical and mental activity improves the quality of life of metastatic cancer patients.** Adrienne uses her knowledge as a former physiotherapist to follow a specific exercise regime, which she finds beneficial. In addition to keeping physically active, Gabriele enrolled as a student, “because I needed to use my brain again” - in a flexible context.

Three Members of the European Parliament took the floor to contribute to the discussion:

- **MEP Anneli Jäätteenmäki** (ALDE, FI) shared personal experience of surviving breast cancer 10 years ago. She stressed the importance of the European Union remaining heavily involved on health issues especially in terms of data collection, exchange of best practices and promotion of screening. She mentioned the high relevance of increasing research on metastatic cancer at the EU level, mainstreaming screening after the age of 50 across all countries, and improving follow-up mechanisms in post-operative scenarios. In this context, MEP Jäätteenmäki referred to the great work conducted by the Joint Research Centre of the European Commission in Ispra.
- **MEP Emma McClarkin** (UK, ECR) shared her experience as a daughter and carer, when her mother died at the age of 48 of breast cancer. MEP McClarkin emphasised the need to focus on patients living with mBC as well as the more usual focus on prevention, and also the need to have plans for carers: “sometimes we forget about people living with the disease who need to maximise their quality of life”; “everyone concerned should be part of a plan”. To achieve this, “the EU should be the melting pot for best practice sharing”. She noted the importance of effective treatment to ensure quality of life. MEP McClarkin also focused on the need to raise awareness to make the voice of metastatic cancer patients heard and invited Adrienne to show the video her organisation had produced at an event at the European Parliament.
- **MEP Deirdre Clune** (IE, EPP) stressed the importance of personal stories like those shared today, sharing survival techniques so that there is more focus on the emotional strength of combating a terminal illness.
- The office of **MEP Karin Kadenbach** (AT, S&D) also noted their interest in the work of these patient advocates.

Amidst a wide-ranging discussion, other comments included the following:

- *Stecy Yghemonos*, Director of Eurocarers, agreed on the importance of the carer’s role. Carers collect information, take care of the patient and have to secure a good management of the work/life balance. In his words, “cancer diagnosis not only happens to patients but carers as well”. Mr. Yghemonos raised the issue of registration of carers and how to define them: different definitions result in between 29 million and 100 million carers in Europe. He also recognised that, according to Eurocarers’ records, there are some countries who offer good support for carers (information, training, financial support, etc) and that could be used as best practice.
- *Ghislaine Lefebvre*, the Head of the Oncology Unit at the Institute Jules Bordet, took the floor to mention the psychological challenge in the fight against cancer and the incidence of returning cancer. She focused on the importance of investing in long-term psychological support.
- *Mihaela Militaru*, Director of the European Cancer Patient Coalition (ECPC), highlighted the work progressing under the Joint Action on Cancer Control (JA CANCON) - Work Package 8 on survivorship and rehabilitation, and the effort made towards a European Survivorship plan. Ms. Militaru highlighted that ECPC members also often raise issues about differences and inequalities in the situation of metastatic cancer patients in Europe. For example, this includes healthcare issues like differences in availability of treatments, but also cultural issues, such as anecdotal examples of partners initiating divorce after diagnosis.



Conclusion

This breakfast was set up to give direct insights into the everyday lives of two people with metastatic cancer. As Tamsin put it, “What can the ‘policy bubble’ do to help stop the world getting smaller for metastatic cancer patients?” Subsequent breakfasts will explore some of the challenges highlighted in this first breakfast in more depth, and begin to explore the policy changes that are needed to address them.



ANNEX 1 – Participant List

Speakers and Moderator

- Gabriele Herzog - Europa Donna Austria
- Adrienne Veraart - Borstkankervereniging Nederland (BVN)
- Tamsin Rose - Moderator

Participants

- Ian Banks -European Cancer Concord
- Liesbeth de Boer - Pfizer
- Jacqueline Bowman Busato- Third-i
- Camille Bulloot - European Patients' Forum
- MEP Deirdre Clune - European Parliament
- Andrea Chiarello - Pfizer
- Vincent Clay - Pfizer
- MEP Anneli Jäätteenmäki - European Parliament
- Agnieszka Krukowska - Johnson & Johnson
- Ghislaine Lefebvre - European Oncology Nursing Society; Institut Jules Bordet
- MEP Emma McClarkin - European Parliament
- Mihaela Militaru - European Cancer Patient Coalition
- Sylwia Staszak – Burson Marsteller
- Paloma Temiño de Dios - Burson Marsteller
- Stecy Yghemonos – Eurocarers
- Petra Wallner – Office of MEP Karin Kadenbach - European Parliament

ANNEX 2 – Speakers' background

Adrienne's latest work captured in the short film, 'The book is not finished yet...', which follows three Dutch patients living with metastatic breast cancer. The film will be subtitled in English within a few months. Trailer: https://www.youtube.com/watch?v=cARC_SrkrTM

Gabriele's personal story available on the Breast Cancer Matters website: <http://www.breastcancer-matters.eu/article/speaking-her-mind-outing-herself-inspire-other-mbc-patients>



ANNEX 3 – Adrienne and Gabriele letter exchange

Dear Gabriele,

Nice to hear your voice during the conference call last Tuesday. I'm looking forward to meeting you in person in Brussels. I introduce myself further in this letter, you can consider it as a warm up to meeting each other 'live'.

I was rather tired after the conference call. To speak in a foreign language is one thing, but to find the right words for my personal experiences and feelings about our bad disease diagnosis, makes it more complicated. Even in Dutch it isn't always easy to find the right words.

As I said last week: I'm a mBC patient for 8 years. I 'celebrate' this jubilee this month. I never thought that I would live so many years after the diagnosis, so I'm a even a little bit lucky. Nevertheless, it isn't easy to deal with it!

I have a theory for myself to cope with the disease: the theory of the two legs. Living is moving. When I want to move (live), I need my two legs. One leg is the leg of the disease, the fear, the sadness. The other one is the leg of doing things I like, like beautiful moments with my family, being angry because of bad political decisions, etc. One day I lean more on the 'disease' leg, for instance when I have a bad outcome from a scan, or when I'm feeling tired and fearful. Another day I'm leaning more on my 'go on' leg. But there must be a connection between the legs and a good cooperation and balance in order to be able to go forward at all. The metaphor of the two legs really describes me. I have liked sports all my life. And.... I was a physiotherapist. I'm an ambassador for our patient group of doing physical exercises during and between treatments. I made a program for the regional TV called: 'Moving and cancer; yes of course?!' At the moment I am joining up with a team of two Universities to develop special physical exercise programs for women with mBC. I also took the initiative to make a film with three different portraits of mBC women. The aim of the film is to show that women are much more than only the disease and that the group isn't homogenous.

I have worked for 6 of the 8 years of illness. When I got the diagnose mBC I was an alderman (member of the daily city administration) in my hometown Bergen op Zoom. You can imagine how my world crashed. After a heavy operation and chemo journey, I restarted my work after three months. In retrospect I'm still wondering how I did it, but I needed the work as a grip in my wounded world.

Two years ago I was forced to stop working. It wasn't easy to do that. Accepting to give up important things/possibilities/activities is one of the most difficult challenges.

To get a glimpse of my personality, I end this letter with messages that that I often hear but I dislike:

'Keep on fighting!' *To what/who should I fight? Cancer is bad luck. To accept that is much more difficult than a Don Quixhote fight against my own body. In the trailer of the film I say: if fighting would help, I would start training immediately!* https://www.youtube.com/watch?v=cARC_SrkrTM

You are a hero! *It looks like that all the cancer patients are 'unconditional heroes'. I hate the atmosphere of heroism around cancer patients. Like we are soldiers in a war! Stop with it please.*

Enjoy your life! *Like we have plenty of time for life like a birthday party. Of course I still have beautiful moments in my life. But chemo treatments and other medicines are dictatorial regimes with no possibilities to be a dissident. Hard to enjoy.*

Gabriele, despite my reactions to these messages, I'm not a cynical person. I laugh a lot and have enough self-irony (luckily for myself and my relatives). No doubt we will have lots to talk about in Brussels!

Best regards, Adrienne



Dear Adrienne,

It was nice to talk to you a few days ago, my first experience of a conference call, which was quite strange, not seeing anybody, but at the end it worked out quite well. I think so!!

My mother tongue is also not English, so we share the same difficulties and others will have to overlook this.

I got my diagnosis on the 21st of May 2012. I will never ever forget that day, because on that day my old life was gone and the new one started. I never asked myself the question "why me?", it just happened to me - my misfortune!

I couldn't find anyone who could explain what to expect in this situation so I found that I had to look for the information by myself. I also thought, that nobody could know what and how much I needed to know about mBC. That's why I think it's also a kind of "sense of responsibility" for patients to get as much input (on mBC) as possible.

Between the first chemo treatments, I tried to go back to work for about 9 months, but it didn't work. I have spent 19 years working in the accounts department of a private company and had to manage quite a lot of money. I just couldn't do it anymore, the responsibility was very high and my brain suffered quite a lot. For me, it was a very good solution as times got harder and when I gave notice of my resignation, nobody was happy. I'm still invited to Christmas parties, barbecues, dart tournaments, etc....

As the following chemo treatments (every three weeks from the beginning) were not that heavy, my hair started to grow again and everybody thought I'm over it and healthy again. Sometimes I explained what mBC is and that it will stay with me for the rest of my life. They just couldn't or didn't want to understand what I told them. Well, I have to say it's not that easy to understand once you are not involved. I was neither an expert in this subject. Now my family and close friends are able to accept it. As I do. It's part of my life and I deal with it as best as I can.

I must say, I can't talk over my mBC with our 22 year old son. It's just not possible. I still think that no mother should ever have to tell their child about such a serious matter.

Because I can't talk to my husband or my son about everything I think or have in mind, I write a diary for each of them. For later!!

I think a lot about my future and have already settled a lot of things that you would normally do when coming of age.

On good days, I'm on my way and do what I want to do. Go to university (I started to study sociology in September 2014), go to the meetings of our BC support group, I'm part of Europa Donna Austria, my husband and I go more often on holidays than before and I enjoy live as far as possible. When days are not that good I stay at home and relax or recover from the efforts of the day. Last year was a hard one I had to go through 5 operations, which was not that nice.

All of my plans have to be made around the hospital appointments every two or three weeks, depending on the therapy. That's hard. That's sometimes like a prison for me. I have to go there if I want to lengthen lifetime! On very odd days I think, "Why do I still go there?" Still, the good things and thoughts outweigh the negatives!!

Now, Adrienne (and the others) I think you've got an impression of my personality. Looking forward to see all of you next week,

Gabriele